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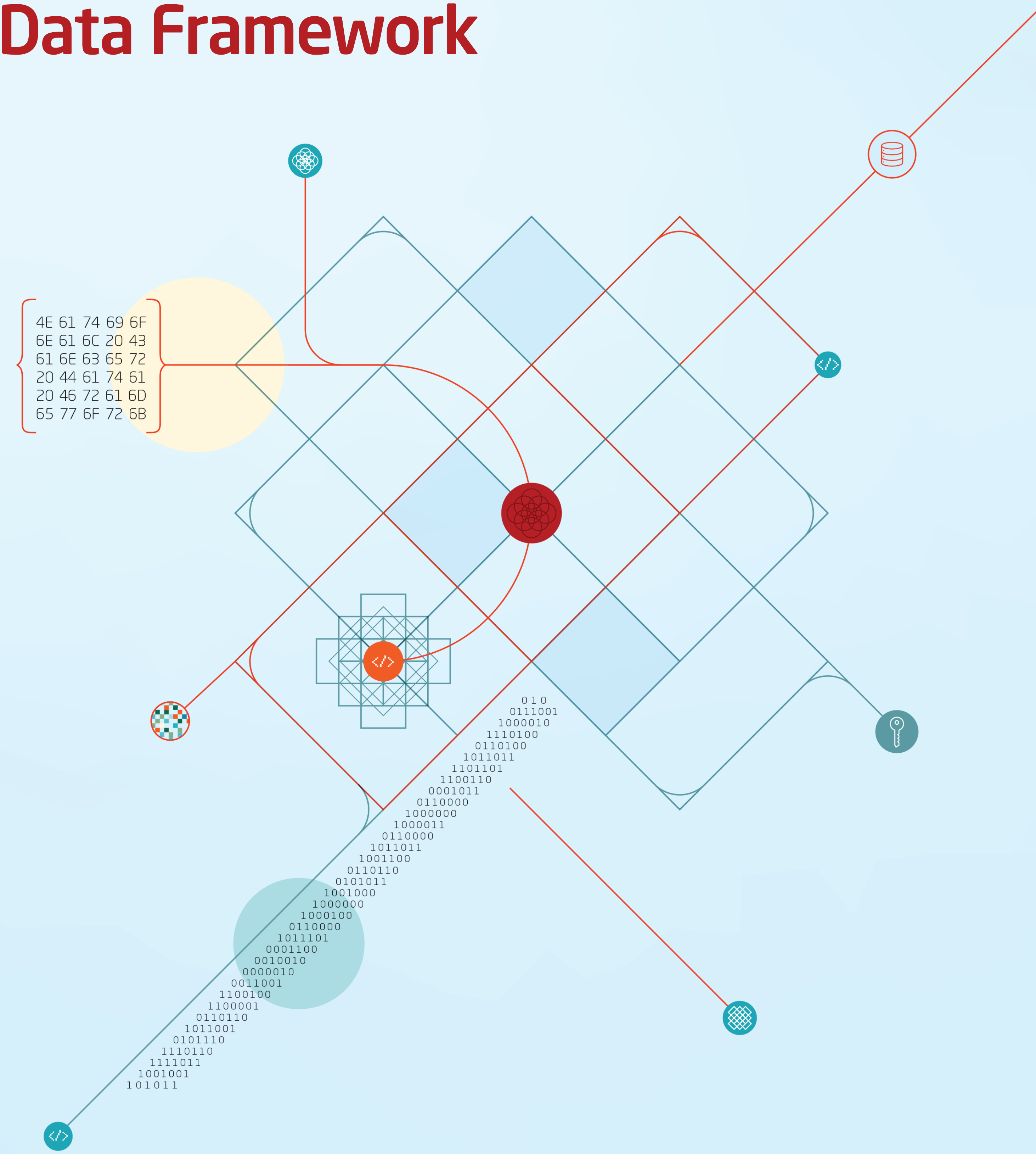
National Cancer Data Framework



Statement of Acknowledgement

Cancer Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of Country throughout Australia. We pay our respects to Elders, past and present.

We celebrate the ongoing connections of Aboriginal and Torres Strait Islander peoples to Country, culture, community, family and tradition and recognise these as integral to health, healing and wellbeing.

Cancer Australia acknowledges great diversity among Aboriginal and Torres Strait Islander peoples, and the contribution of the many voices, knowledge systems and experiences that guide all efforts to create a culturally safe and responsive cancer system that is equitable to all.

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Acknowledgements

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We thank all state and territory governments, data custodians, health professionals, clinicians, public and private health providers, not-for-profit organisations, professional colleges, research and clinical trial groups and consumers for their valuable contribution and advice. We also acknowledge and respect the contributions made by the Aboriginal and Torres Strait Islander representatives who participated in the First Nations-led co-design process and whose perspectives have been vital in the development of the Data Framework. We also thank the National Cancer Data Framework Steering Committee for their advice, which has guided and enhanced the framework's accessibility, consistency and comprehensiveness.

Minister’s Foreword

As Minister for Health and Ageing, I am pleased to present the National Cancer Data Framework, a crucial initiative developed by Cancer Australia in partnership with the Australian Institute of Health and Welfare and Cancer Council Australia. This framework represents an important step forward in ensuring we have the robust data and evidence needed to drive world-class cancer outcomes in Australia. It delivers a key action of the Australian Cancer Plan, underpinning the Plan’s strategic objective to establish strong and dynamic foundations for cancer control across the nation.

A mature cancer data system in Australia will improve patient outcomes by providing a holistic view of the care continuum. This system will enable optimised care pathways, enhanced clinical decision-making, by identification of disparities in access to diagnosis and treatment. By enabling evaluation of prevention strategies and screening impacts, it will lead to more effective interventions and earlier detection. The ability to compare outcomes will facilitate the identification and dissemination of best practices, while timely real-world data will allow for responses to emerging challenges. The Data Framework provides the basis to capture the essential data needed to answer critical questions about cancer control, improve equity in healthcare access, and offer insights into health system performance that will enhance Australia’s overall cancer outcomes.

Developed through extensive sector consultation, this Data Framework integrates multiple perspectives to enhance cancer data collection, integration, and utilisation across the country. It represents a sector-wide consensus on the need for a mature cancer data ecosystem.

Along with setting the strategic direction for the consistent collection, management and use of cancer data, this Framework aligns with key national health data and digital reforms, including the Digital Health Blueprint and National Digital Health Strategy, ensuring an integrated and secure approach to data collection and sharing.

Improving cancer data is a whole-of-sector responsibility. The strong support for this Data Framework underscores its importance in addressing the issues that have hindered improvements in cancer data. By connecting data across the cancer continuum and addressing inequity issues in the system, we will underpin the broader success of the Australian Cancer Plan.

I am confident that this National Cancer Data Framework will drive data-informed enhancements in patient care, service delivery, and research support across our cancer care system, ultimately leading to better outcomes for all Australians affected by cancer.

The Hon Mark Butler MP
Minister for Health and Ageing

Executive summary

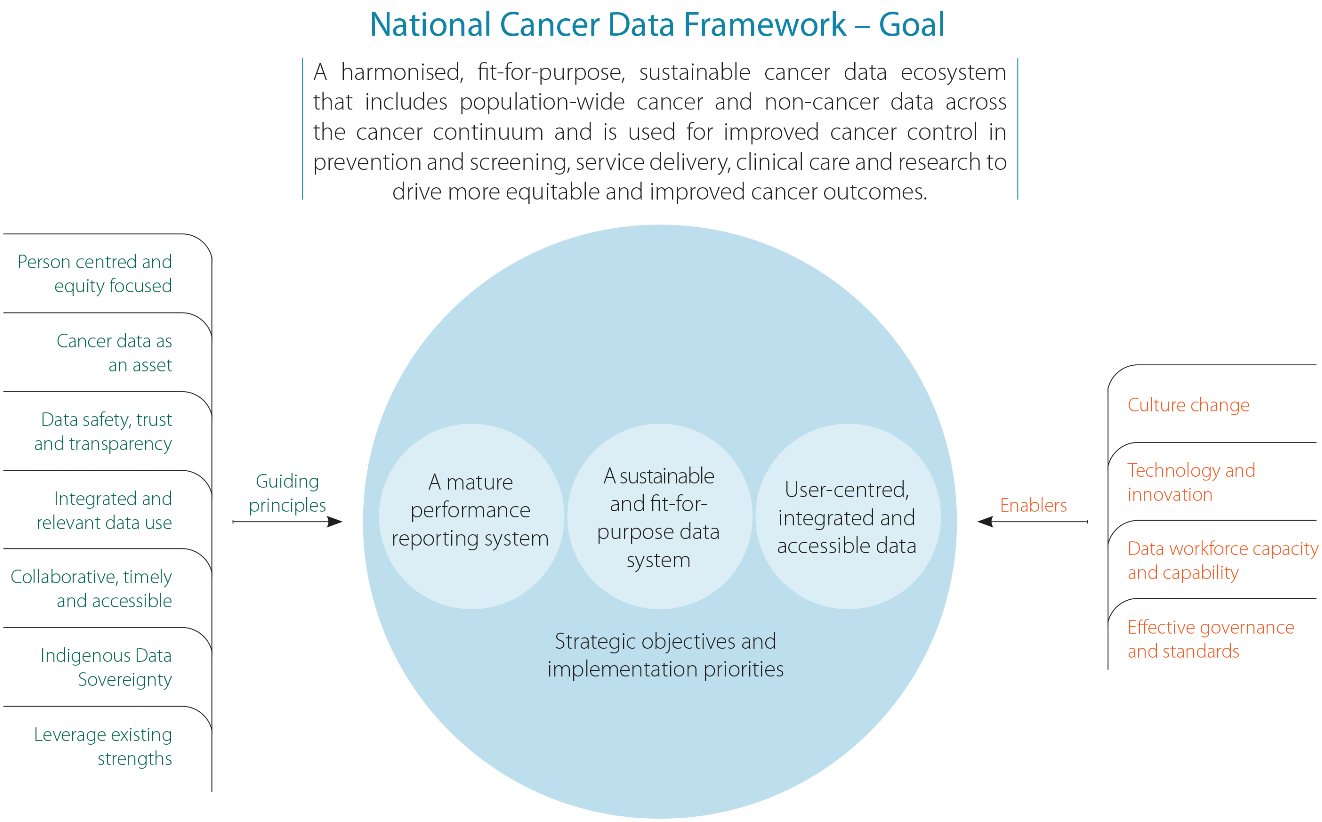
Cancer represents Australia's largest disease burden and is a leading cause of death. Over one million Australians currently live with or have lived with cancer.[1] In response, the Australian Government released the Australian Cancer Plan[2] in 2023, aiming to improve outcomes for all Australians, particularly those facing poorer health outcomes. Achieving equity in cancer outcomes is a fundamental measure of success as we strive for world-class cancer care for all Australians.

The Australian Cancer Plan emphasises that optimal cancer care and a high-performing system rely on access to, use of and sharing of reliable and comprehensive health and cancer data across all care settings. While Australia has rich and diverse cancer data collections, their effective use is hindered by fragmentation, complex governance arrangements, and variation in data collection. The sector needs to work together to improve data availability and better measure how well the healthcare system is performing.

The National Cancer Data Framework (Data Framework) will set the strategic direction for the collection, management, use and ongoing development of comprehensive and consistent health and cancer data. It aligns closely with several key initiatives and priorities in Australia's cancer control and data landscape, supports the strategic objectives of the Australian Cancer Plan, and builds on the broader government digital health agenda, including aspirations for seamless data use across patient care and secondary research, as outlined in the Digital Health Blueprint and National Digital Health Strategy.

The Data Framework's development has been informed by extensive sector consultation, reflecting broad national agreement on the current state of cancer data in Australia and priorities for action. It incorporates Indigenous Data Sovereignty principles to ensure that the unique health needs of First Nations peoples are met.

Figure 1: The guiding principles and enablers of the Data Framework, with three strategic objectives to achieve its overarching vision



National Cancer Data Framework – Goal

A harmonised, fit-for-purpose, sustainable cancer data ecosystem that includes population-wide cancer and non-cancer data across the cancer continuum and is used for improved cancer control in prevention and screening, service delivery, clinical care and research to drive more equitable and improved cancer outcomes.

The Data Framework includes three strategic objectives to improve cancer care in Australia: a mature performance reporting system; a sustainable and fit-for-purpose data system; and user-centred, integrated and accessible data.

A mature performance reporting system

The first objective is to create a mature performance reporting framework that measures system performance across the entire cancer care continuum. The framework will address critical questions regarding prevention strategies, screening impacts, equity in access to diagnosis and treatments, and outcomes for priority populations. By leveraging existing frameworks, this objective aims to identify variations in care, to inform interventions and policy decisions, ultimately enhancing patient care.

A sustainable and fit-for-purpose data system

The second objective is to build a mature and sustainable data system that collects timely and accurate information about cancer care. By standardising the way data is collected, it will make information sharing quicker and easier. This objective will help fill information gaps, such as how advanced cancer is when it is first found, to help improve care for patients. Getting this information more quickly will help with clinical decision-making and service- and system-level planning.

User-centred, integrated and accessible data

The third objective is to create a user-centred data system that is easy to access and allows linking of data between national and local levels. Streamlining approval processes will make it simpler to use this data while keeping it safe and reliable. Connecting information from different parts of a patient's journey will enable a full picture of their cancer care and outcomes. Achieving these strategic objectives will be key milestones in realising the 10-year vision of the Australian Cancer Plan. The Data Framework aims to provide essential data to address key questions in cancer control. It will improve equity in healthcare access and offer insights into health system performance to enhance cancer outcomes across Australia.

Plan on a page

Australian Cancer Plan ten-year ambition

A modern, fit-for-purpose cancer control infrastructure, advanced by the innovative application of technology, research and data to improve Australia's cancer outcomes.

National Cancer Data Framework – Goal

A harmonised, fit-for-purpose, sustainable cancer data ecosystem that includes population-wide cancer and non-cancer data across the cancer continuum and is used for improved cancer control in prevention and screening, service delivery, clinical care and research, to drive more equitable and improved cancer outcomes.

Guiding principles

Person centred and equity focused: Data are used to provide person-centred treatment and care, delivering the best outcomes and improved equity for all Australians, focusing on First Nations peoples, priority population groups and their communities.

Indigenous Data Sovereignty: First Nations peoples have the right to exercise ownership over First Nations data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, governance, dissemination and reuse of First Nations data.

Cancer data as an asset: Acknowledging that Australia requires a cancer data ecosystem that is accessible through modern infrastructure, enables collaboration to inform policy and health service delivery, drives economic value, supports innovation and improves cancer outcomes for all Australians.

Leverage existing strengths: Strategic objectives and priority actions align with, build on and add to initiatives and innovations in policy approaches to data capture and sharing that can be harnessed and scaled.

Data safety, trust and transparency: Personal data are protected, and public reporting is transparent, helping to build community trust in reporting on progress in cancer outcomes and effectively addressing inequities.

Collaborative, timely and accessible: Making cancer data timely and accessible through modern infrastructure and streamlined data governance enables collaborative efforts across the whole cancer sector.

Integrated and relevant data use: Data access is enabled, data-driven decision-making is embraced and data collection is promoted as part of patient care through seamless integration into clinician workflows.

Strategic objectives and implementation priorities

1. A mature performance reporting system

Transparent reporting of cancer control indicators will drive improvements in prevention, screening, diagnosis, treatment and palliative care. Australia's capacity to use data to reduce the incidence of cancer and improve survival from cancer is reliant on public trust that data are collected, stored and used safely.

1.1 Indigenous Data Sovereignty and Governance for improved First Nations community outcomes.
1.2 Build and maintain public trust in the data system.
1.3 Establish a robust cancer control monitoring and benchmarking system to drive optimal care.

2. A sustainable and fit-for-purpose data system

Foster a sustainable and fit-for-purpose data system that enables the timely collection of health and population data inclusive of cancer and non-cancer data, collected across the ecosystem using nationally consistent standards to facilitate system interoperability and greater information exchange across the continuum of care and across jurisdictions.

2.1 Embed and implement the governance of First Nations data in the cancer data ecosystem.
2.2 Improve the timeliness of cancer data collection and reporting.
2.3 Strengthen existing mechanisms to ensure consistent and valid collection of key cancer data within Australian cancer registries.
2.4 Advance the collection of cancer stage at diagnosis data as a key measure of equity and cancer control.
2.5 Agree and prioritise national data gaps.
2.6 Collect standardised national cancer data to support reporting on priority needs, including optimal cancer treatment and care, equity and patient outcomes and experiences.
2.7 Enhance the capture of structured pathology and radiology reporting, for consistent data capture from source systems.
2.8 Explore the potential for structured clinical reporting of key data items within digital health systems.

3. User-centred, integrated and accessible data

Deliver a user-centred, integrated and accessible data system that incorporates longitudinal data to track changes over time, through the timely, streamlined and safe promotion of trusted, transparent and advanced data-sharing arrangements using integrated data assets at national and jurisdictional levels.

3.1 Ensure enduring data linkages and associated access, as well as research, is overseen with appropriate Aboriginal and Torres Strait Islander ethical practices.
3.2 Enhance data access through effective and efficient data governance and streamlined ethics approvals.
3.3 Adopt a harmonised approach to enduring integrated data assets that safely enable rapid access by accredited end users, while ensuring data safety, quality and reliability.

Enablers

Culture change

Technology and innovation

Data workforce capacity and capability

Effective governance and standards

Introduction

Cancer represents Australia's largest disease burden and is a leading cause of death. Over one million Australians are currently living with or have lived with cancer, and projections for 2025 indicated 169,759 new cancer diagnoses and 53,545 cancer-related deaths.[1, 3] These figures exclude non-melanoma skin cancers, which would significantly increase the total.

In response, the Australian Government released the Australian Cancer Plan[2] in 2023, aiming to improve outcomes for all Australians, particularly those with poorer health outcomes. Achieving equity in cancer outcomes is a fundamental measure of success as Australia strives for **world-class cancer outcomes and experiences for all Australians**.

Text Box 1: The Australia Cancer Plan

Strong and Dynamic Foundations

Ten-year ambition: A modern, fit-for-purpose cancer control infrastructure, advanced by the innovative application of technology, research and data to improve Australia's cancer outcomes.

Two-year goal: Nationally agreed frameworks for collection and reporting of comprehensive cancer data, and implementation of new technologies into routine cancer care, with a focus on research priorities that drive innovation and fast-track opening of cancer clinical trials in Australia.

Action: Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets.

The Australian Cancer Plan emphasises that optimal cancer care and a high-performing system rely on access to, use of and sharing of comprehensive health and cancer data across all care settings (Text Box 1). This data is crucial for informing planning, delivery and continuous improvement of cancer care, as well as driving policy and research priorities across the cancer control continuum.

While Australia holds rich and diverse cancer data collections, their effective use is hindered by the segmented structure of the healthcare system (public and private) and other structural and legislative factors. These include multiple data custodians, complex governance arrangements, and a lack of harmonisation across population-based datasets, which prevent compilation of complete national data collections and challenge Australia's ability to create a nationally consistent view of cancer control.

Addressing these challenges requires a concerted effort to improve data availability, enhance performance measurement and reporting frameworks, and prioritise strength-based, person-centred healthcare metrics nationally. These steps are essential for achieving more consistent and improved cancer care outcomes for all Australians and require whole-of-sector action.

The development of a National Cancer Data Framework is a key action towards a two-year goal under the Strong and Dynamic Foundations objective of the Australian Cancer Plan. This Data Framework will set the strategic direction for the collection, management, use and ongoing development of comprehensive and consistent health and cancer data. It aims to ensure Australia has a mature cancer data ecosystem that supports reporting and benchmarking of key cancer control performance indicators, embeds Indigenous Data Sovereignty, underpins data-driven improvements to patient care, and supports world-class research.

The Data Framework complements other Australian Cancer Plan strategic objectives and implementation priorities, including the National Optimal Care Pathways Framework and National Framework for Genomics in Cancer Control. It aligns with national, and state and territory data, digital and cyber-related policies and long-term reforms, supported by cross-jurisdictional commitments that acknowledge this is a shared responsibility (Text Box 2).

These reforms will create opportunities to support the implementation of the Data Framework, contributing stronger safeguards and more efficient processes, and fostering innovation to grow the national cancer data asset for the benefit all Australians.

Text Box 2. Strategic policy context - national data and digital reforms

Strategic policy context

All governments across Australia recognise the value of data for evidence informed decision making and have committed to long-term reforms to improve national data sharing, including through:

- The Intergovernmental Agreement on Data Sharing between Commonwealth and State and Territory Governments,[4] which commits all governments to share public-sector data by default, where it can be done securely, safely, lawfully and ethically.
- The Intergovernmental Agreement on National Digital Health 2023–2027,[5] which focuses on enabling interoperability and connected data across health care settings. It also commits all governments to support development of national health information exchange capabilities.
- The 2020–25 National Health Reform Agreement,[6] which commits all governments to improve health outcomes and ensure the sustainability of the health system. The associated Long-term Health Reforms Roadmap[7] includes actions to enhance national health data.
- The National Digital Health Strategy (2023–2028),[8] which sets the vision and pathway for Australia's digital health future, aiming to create a more connected, person-centred digital health system.
- The National Digital Health Blueprint (2023–2033),[9] which aims to create a more connected and sustainable health system by improving data access, promoting interoperability and using technology for personalised healthcare.
- The Data and Digital Government Strategy,[10] which sets the Australian Government's ambition and expectations for the Australian Public Service's data and digital transformation.
- The 2023–2030 Australian Cyber Security Strategy,[11] which aims to improve Australia's national resilience to cyber threats and responses to cyber incidents.
- The review of the *Privacy Act 1998* and the Government Response: Privacy Act review report,[12] which has prompted actions to strengthen the Act's approach to protecting personal information. The Australian Government is working with state and territory governments to harmonise elements across their respective privacy laws.
- The National Agreement on Closing the Gap[13] Priority Reform four, which aims to ensure data and information are shared and made available to Aboriginal and Torres Strait Islander people, to enable communities to access and use locally-relevant data and information to set and monitor implementation efforts to close the gap.
- The Australian Framework for National Clinical Quality Registries 2024,[14] which supports clinical quality registries in collecting, analysing, and reporting clinical data, to maximise the value of Australia's clinical quality outcomes data.
- Office of the National Data Commissioner (ONDC) guidance and initiatives, including:
    - the Foundational Four[15] minimum data governance standards
    - the DATA Scheme – a new, best practice scheme for sharing Australian Government data, established through the Data Availability and Transparency Act 2022[16]
    - the Dataplace platform, which manages data sharing requests for the Australian Government and hosts the Australian Government Data Catalogue.

Why cancer data matters

Cancer data plays a vital role in supporting decision-making and improving cancer outcomes across Australia. A comprehensive and integrated cancer data system enables evidence-based decisions, identifies care disparities, and supports targeted interventions. Moreover, it fills gaps and connects data to provide a longitudinal view of patients and priority populations across all interactions with the health system, moving away from episodic care. By increasing understanding of risk factors and their relationship with cancer, data informs prevention strategies that can reduce cancer incidence and promote early detection.

The routine collection of real-world data from cancer registries and patients helps build a real-world evidence base. Standardised data collection, particularly for priority populations, will facilitate a comprehensive national view of cancer control efforts and work towards a national benchmarking capability that will drive system improvements in cancer care and improve the health system's ability to identify and address inequities.

Cancer data, when linked to population-level indicators and performance measures, will enable the identification of disparities and tracking of progress in reducing them. This approach allows for targeted interventions and resource allocation to areas of greatest need. For instance, variations in cancer screening rates, treatment outcomes and survival can be monitored across different population groups and geographic regions.

Other data, such as health system expenditure and burden of disease data, are critical for understanding the broader impacts of cancer. For example, publications such as the Australian Institute of Health and Welfare (AIHW) report *Health system expenditure on cancer and other neoplasms in Australia, 2015–16*[17] and the Australian Burden of Disease Study[3] reports provide key insights into these areas. Additionally, expenditure data are embedded within existing datasets, including the Medical Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS). Incorporating such data into the cancer data ecosystem underscores the value of cancer-related economic and health burden insights in shaping policy, resource allocation, and service delivery.

Text Box 3: Cancer data audience

Patients, their cancer care team, including primary care, and communities leverage data for personalised care, leading to improved patient outcomes and experiences. The data provides clear information on diagnosis, treatment, follow-up care, and recovery.

Researchers draw on population-based data and share their datasets to advance cancer care and make innovative discoveries. This collaborative research, facilitated by integrated data systems, accelerates progress in the field, including clinical trials.

Health administrators require data to inform decisions on improving the availability, quality, equity and outcomes of healthcare services.

Policymakers rely on data for evidence-based decision-making, resource allocation, equity considerations and policy impact monitoring.

Investing in comprehensive data collection, integration and sharing will enhance the health system's effectiveness in meeting the diverse needs of Australians. This data serves various stakeholders, each with different needs: patients, caregivers and their communities use it for informed decision-making about care options; cancer care teams rely on it for clinical decision-making and quality improvement; researchers use it to identify trends and develop new strategies; health administrators use it for resource allocation and system planning; and policymakers use it to develop evidence-based policies and monitor cancer control efforts (Text Box 3).

Indigenous Data Sovereignty and Governance

Indigenous Data Sovereignty refers to the inherent rights of Aboriginal and Torres Strait Islander peoples to exercise control over the data related to them. This encompasses the entire data lifecycle, from conceptualisation, creation and collection through to analysis, interpretation, dissemination and ownership. The development of this Data Framework is guided by the Maiam nayri Wingara (2018)[18] principles on Indigenous Data Sovereignty, ensuring that the rights of First Nations people are respected and enabled throughout the entire data lifecycle. These principles assert that First Nations people have the right to:

- exercise control over the data ecosystem, including creation, development, stewardship, analysis, dissemination and infrastructure
- access contextual and disaggregated data at individual, community and First Nations levels
- ensure data relevance that empowers sustainable self-determination and effective self-governance
- establish data structures accountable to Indigenous peoples and First Nations
- protect and respect individual and collective interests in data.

The Indigenous Data Sovereignty principles establish a framework that addresses the marginalisation and exclusion of First Nations communities from their data. This is essential to address the unique health challenges of First Nations communities while setting a benchmark for inclusive, equitable, ethical and effective data utilisation. This approach creates opportunities that benefit all population groups across Australia for more informed, culturally sensitive and effective health strategies across diverse communities.

Text Box 4: Priority Reform Four – Shared Access to Data and Information

Priority Reform Four of the Closing the Gap Agreement ensures Aboriginal and Torres Strait Islander peoples can access and use locally relevant data. It empowers Indigenous communities to monitor progress, drive development and prioritise their needs. By promoting shared access to data at a regional level, Indigenous peoples are enabled to make informed decisions and track progress more effectively.

The Data Framework considers Indigenous Data Sovereignty and Indigenous Data Governance in each objective, through operationalising Indigenous Data Sovereignty. This will require significant data capability building and governance supports across First Nations communities.

It is acknowledged that implementing Indigenous Data Sovereignty for retrospective datasets is challenging but not unachievable. These datasets were often collected without the involvement or consent of First Nations communities, and at present may not align with Indigenous Data Sovereignty principles. Importantly, Indigenous Data Sovereignty and Indigenous Data Governance occur within the community, as opposed to the governance of Indigenous data, which occurs within government. Indigenous Data Sovereignty and Indigenous Data Governance are achieved through partnership with First Nations people across the data lifecycle.

Addressing these challenges requires careful consideration of how to integrate First Nations governance practices into existing and new data governance structures. This is considered throughout the Data Framework. It is important to ensure that historical and future data is managed in a way that respects the rights and interests of First Nations peoples, and that it can be used to support their self-determination and governance.

The Data Framework aligns with and builds upon key national initiatives, including Priority Reform Four of the National Agreement on Closing the Gap[19] (Text Box 4), the National Aboriginal Community Controlled Health Organisation (NACCHO) Aboriginal and Torres Strait Islander Cancer Plan,[20] and the Australian Cancer Plan. The Data Framework outlines tangible actions that will support improved reporting and analysis of cancer data used in the Aboriginal and Torres Strait Islander Cancer Control Indicators and the Aboriginal and Torres Strait Islander Health Performance Framework.

Development of the Data Framework

The Data Framework has been developed by Cancer Australia in a collaborative partnership with the AIHW and Cancer Council Australia.

The Data Framework was informed by advice from the National Cancer Data Framework Steering Committee, state and territory governments and Cancer Australia's advisory groups; through a series of national roundtables representing state and territory governments, data custodians, clinicians, public and private health providers, not-for-profit organisations, professional colleges, research groups, research and clinical trial groups and consumers; and through an open public consultation process.

The Data Framework has been developed **in a way that embeds best practice principles for co-design with First Nations Australians**.[21] This was informed by a First Nations-led co-design process with First Nations leaders, practitioners and community members, ensuring the Data Framework and implementation remain culturally appropriate, effective and aligned with community values.

The goal of the National Cancer Data Framework

> *A harmonised, fit-for-purpose, sustainable cancer data ecosystem that includes population-wide cancer and non-cancer data across the cancer continuum and is used for improved cancer control in prevention and screening, service delivery, clinical care and research, to drive more equitable and improved cancer outcomes.*

Achieving the goal of this Data Framework will be a significant milestone in realising the 10-year ambition of the Australian Cancer Plan for a 'A modern, fit for purpose cancer control infrastructure, advanced by the innovative application of technology, research and data to improve Australia's cancer outcomes'. It will make available the data needed to answer Australia's critical cancer control questions, improve equity and provide insights into health system performance that will improve Australia's cancer outcomes.

Current state

Australia holds rich and diverse cancer data collections that offer valuable insights into cancer trends and outcomes. Jurisdiction-based cancer registries provide population-wide data on incidence, mortality, survival and prevalence, compiled into the Australian Cancer Database.[22] Clinical quality registries complement this with detailed patient care and outcome data, though their focus and coverage vary. Administrative datasets, hospital and health service data, research data and surveys further contribute to understanding cancer care and outcomes. The cancer data ecosystem visually represents this complex network, showcasing the various datasets, their respective custodians and the connections between them (Figure 2). It illustrates how data flows across different stages of the cancer care continuum, from prevention and screening through to diagnosis, treatment and outcomes.

Despite these strengths, the current cancer data system faces several key challenges:

- **Fragmentation:** Data capture across cancer services, primary care, screening registers and administrative databases is inconsistent. This fragmentation limits the ability to achieve a nationally consistent, data-driven understanding of cancer control and outcomes.
- **Interoperability:** Limited interoperability between data systems across states, territories and jurisdictions, and other non-technical barriers, hinders seamless data exchange. Achieving interoperability would ensure

consistent, accurate data across systems, reduce errors and redundancies and eliminate most manual data entry, while improving the timeliness of information.

- **Data gaps:** Critical gaps exist in national cancer data, particularly in areas such as cancer stage at diagnosis, patient-reported outcomes, treatment measures, and service quality indicators. Additionally, integrating genomics data is increasingly important for identifying individual cancer risk, early detection, and personalised treatment options.
- **Data linkages and access:** Linking cancer data with other relevant datasets, such as those covering social determinants of health, is often costly, delayed and complex. Differing ethics and access requirements from multiple data custodians add to the difficulty. National initiatives like the National Health Data Hub (NHDH)[23] and the Person Level Integrated Data Asset (PLIDA)[24] aim to improve linkages, but more regularly updated and accessible datasets are needed to understand variations in outcomes, especially for priority populations.
- **Underutilisation of research data:** A significant amount of valuable data is generated from cancer research and clinical trials, including genomics information. However, this data is often underutilised, limiting its potential to inform clinical practice, guide future research and generate further insights.
- **Limited reporting:** Despite the extensive cancer data collected in Australia, there is no standardised or mandatory system for performance measurement and reporting. This hinders benchmarking and the identification of improvement opportunities. Much of the data generated by patients and health providers on the cancer journey remains unreported and uncollated, reducing its potential to drive better health care and outcomes.

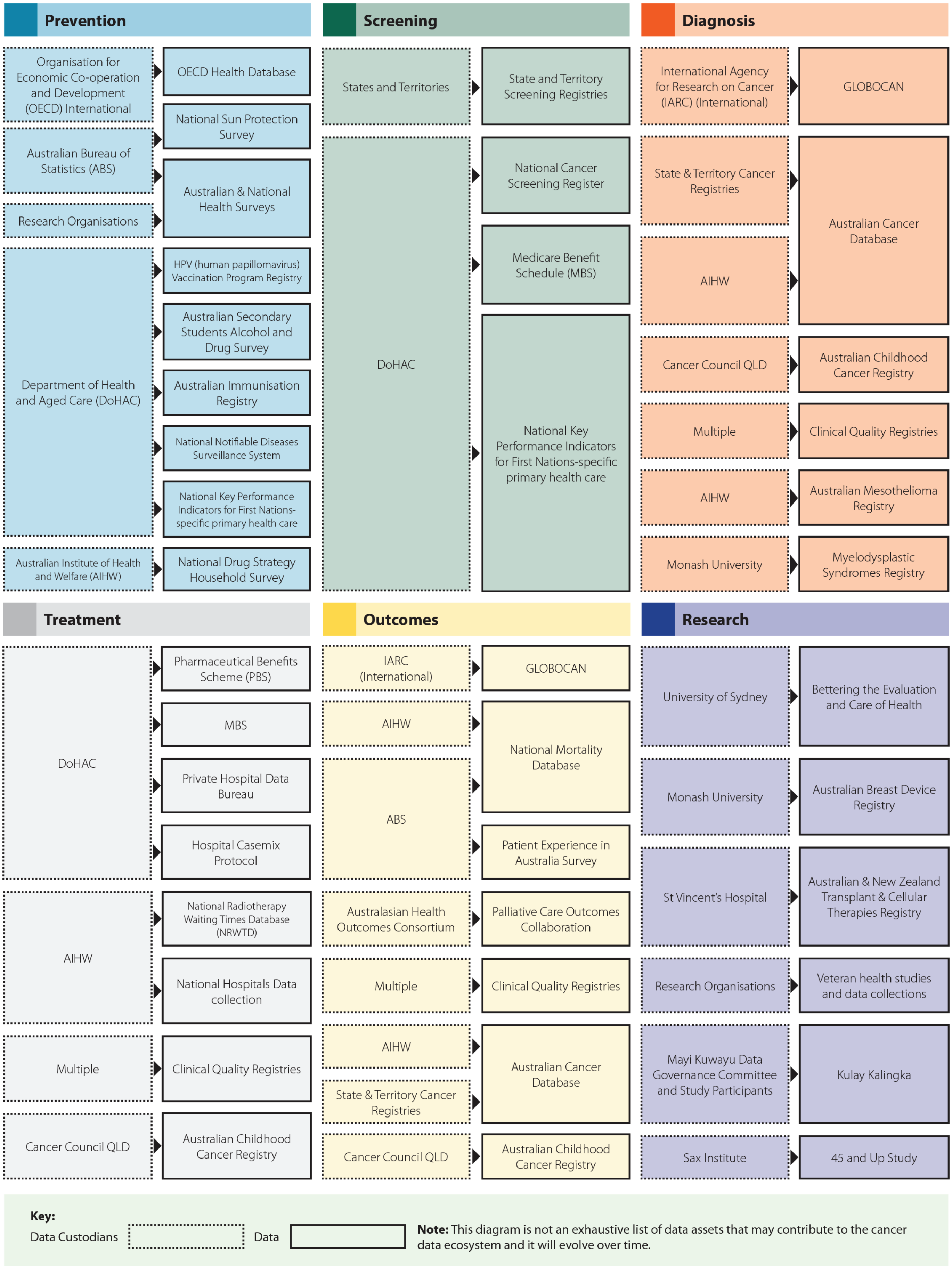
There is a large amount of data captured in digital health systems, primary care, hospitals, pathology, radiology, radiation oncology, veteran records and clinical trials, as well as biobanks, that can be used to strengthen the cancer data ecosystem if standardised and integrated well.

Efforts to standardise data collection across the cancer care continuum are essential to improving data quality, timeliness, completeness and interoperability. Standardisation will help identify variations in stage at diagnosis, non-stage prognostic factors, treatment, and outcomes, and will improve equity in cancer care.

Achieving full interoperability across systems would not only facilitate seamless data exchange but also ensure consistent and accurate data across all platforms, enhancing the potential for improving patient care, service planning, and system performance, reducing errors, and strengthening national cancer control efforts. Furthermore, consideration will need to be given to non-technical barriers that may relate to legal, governance or other disincentives to share.

The cancer data ecosystem demonstrates the various data sources and custodians involved in cancer care, highlighting the need to integrate diverse datasets for a unified view of cancer control (Figure 2).

Figure 2: Australia’s Cancer Data Ecosystem



Note: This diagram is not an exhaustive list of data assets that may contribute to the cancer data ecosystem and it will evolve over time.

Guiding principles

These guiding principles shape the development and ongoing implementation of the Data Framework, ensuring it remains adaptable as Australia's cancer data system matures.

- **Leverage existing strengths:** Strategic objectives and priority actions align with, build on and add to existing initiatives and innovations in policy approaches to data capture and sharing that can be harnessed and scaled.
- **Indigenous Data Sovereignty:** First Nations people have the right to exercise ownership over First Nations data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, governance, dissemination and reuse of First Nations data.
- **Cancer data as an asset:** Acknowledging that Australia requires a cancer data ecosystem that is accessible through modern infrastructure enables collaboration to inform policy and health service delivery, drives economic value, supports innovation and improves cancer outcomes for all Australians.
- **Person centred and equity focused:** Data are used to provide person-centred treatment and care, delivering the best outcomes and improved equity for all Australians, focusing on First Nations people, priority population groups and their communities.
- **Data safety, trust and transparency:** Personal data are protected, and public reporting is transparent, helping to build community trust in reporting on progress in cancer outcomes and effectively addressing inequities.
- **Collaborative, timely and accessible:** Making cancer data timely and accessible through modern infrastructure and streamlined data governance enables collaborative efforts across the whole cancer sector.
- **Integrated and relevant data use:** Data access is enabled, data-driven decision-making is embraced and data collection is promoted as part of patient care through seamless integration into clinician workflows.

Strategic objectives

This Data Framework outlines three strategic objectives to support improvements to cancer data nationally and ensure Australia has a mature data ecosystem that supports data-driven improvements to cancer control across the length of the cancer care continuum, including improving system performance. They provide the foundation for delivering on the goal of this Data Framework.

Implementation priorities sit underneath each strategic objective to guide where action is required. Achieving the goal of the Data Framework requires sector-wide collaboration and partnerships between governments, consumers and carers, Aboriginal and Torres Strait Islander communities and leaders, data custodians, health professionals, clinicians, public and private health providers, non-government organisations, research groups, and professional colleges.

Strategic Objective 1: A mature performance reporting system

> *Transparent reporting of cancer control indicators will drive improvements in prevention, screening, diagnosis, treatment and palliative care. Australia's capacity to use data to reduce the incidence of cancer and improve survival from cancer is reliant on public trust that data are collected, stored and used safely.*

This objective aims to develop a mature, trusted performance reporting system that measures cancer control system performance across the entire continuum while addressing the needs of priority populations.

This will be achieved through a mature national cancer control performance reporting framework, measuring key indicators assessable against the cancer control continuum and Optimal Care Pathways. The Data Framework will address critical cancer control questions such as the effectiveness of prevention strategies; the reach and impact of screening programs; equity in access to diagnosis and treatment, including health care costs; outcomes of cancer care; support for survivors and palliative care patients; and disparities among priority populations.

Leveraging existing frameworks like the National Cancer Control Indicators (NCCI) (and associated Aboriginal and Torres Strait Islander Cancer Control Indicators) and Australian Health Performance Framework (AHPF) will be crucial to developing a mature national cancer control performance reporting framework. The NCCI and Aboriginal and Torres Strait Islander Cancer Control Indicators track indicators across the cancer care continuum and support international benchmarking, while the AHPF provides data for evaluating health system performance and intervention effectiveness.

The comprehensive framework will enable population-level cancer surveillance and support improvement efforts at various levels through enhanced data use. The goal is a transparent, trusted system that improves patient care by answering these critical questions and informing targeted interventions and policy decisions.

Importance

Monitoring and reporting on cancer control system performance enhances our understanding of its effectiveness against optimal cancer pathways, guiding future efforts. Population-level cancer surveillance and performance reporting are critical for identifying gaps leading to unwarranted variations in incidence, diagnosis and outcomes, informing improvement efforts.

This is particularly crucial for Aboriginal and Torres Strait Islander people, who face higher cancer diagnosis and mortality rates and lower 5-year relative survival compared to non-Indigenous Australians. For First Nations communities, aligning data practices with self-determination is essential to accurately capture and address their unique health challenges and outcomes.

Internationally, cancer care system performance reporting is well developed in some countries, as highlighted by the International Cancer Benchmarking Partnership (ICBP).[25] The ICBP measures variations in cancer survival, incidence and mortality across countries to identify best practices and inform policy changes. Australia can benefit from adopting ICBP practices that contribute to improved cancer outcomes.

Current challenge

Achieving robust performance reporting is challenging, requiring consideration of system-level factors (e.g. service access), person/community-level factors (e.g. social determinants, health behaviours), and disease/treatment-level factors (e.g. stage at diagnosis, treatment appropriateness). Accounting for this complexity is crucial to understanding cancer outcome variations across populations and informing improvement efforts. For First Nations communities, effective implementation of Indigenous Data Governance to support local service improvement is essential, considering tailored needs and interests.

In Australia, national cancer surveillance and performance reporting are hampered by:

- lack of a comprehensive national performance monitoring framework including service quality indicators
- unstandardised data collection, analysis and reporting approaches
- complex, unconnected data holdings across public and private systems, including primary care, clinical cancer registries, trial and research datasets
- complex data custodian arrangements, particularly for cross-custodian linkage.

Strengthening foundations for growth

Several jurisdictions are advancing cancer surveillance and system performance reporting. Highly developed approaches are the NSW and ACT program Reporting for Better Cancer Outcomes[26] and Queensland's Cancer Alliance Cancer Control Quality and Safety Partnership.[27] Various strengths are also evident in other jurisdictions. Both the NSW/ACT and Queensland approaches emphasise clinician leadership and collaboration but differ in focus: NSW covers prevention, screening, treatment and research, while Queensland concentrates on specific cancer types.

To build on these strengths, Australia's cancer care system needs increased cross-jurisdictional collaboration to assess real-world impacts of investments across the cancer care continuum.

Implementation priorities and actions

1.1 Indigenous Data Sovereignty and Governance for improved First Nations community outcomes

It is essential for First Nations communities to have a clear understanding of the available cancer data in the cancer data ecosystem, including data types, custodians and reporting options. This understanding extends to knowing and comprehending existing cancer control indicators, as well as being actively engaged in the development of new indicators that are relevant and meaningful to their communities.

Aligning data use with Indigenous Data Sovereignty principles enables First Nations communities to determine the reporting that is important to them, which can then be leveraged to support decision-making and influence health outcomes. This process involves building data-related capabilities and enhancing knowledge of data assets, supporting self-determination and informed choices. Indigenous Data Governance across the data lifecycle is covered under action 2.1.

1.2 Build and maintain public trust in the data system

Public trust is essential for the Data Framework's success. Achieving this trust requires transparency, understanding and empowerment. This can be achieved by partnering with the public to ensure a clear understanding about what data is collected, how it is used and how to access it. Given concerns about data breaches and cyber security, earning trust also requires demonstrating ethical practices, respecting privacy, and highlighting the benefits of transparent reporting.

A key outcome is improved health literacy about the value of aggregated data and performance reporting for public benefit. Ensuring responsible data use, particularly for priority groups, will build confidence in data initiatives. Meaningful engagement with the public and stakeholders will foster collaboration. Harmonised approaches to data use and reporting will further enhance public trust.

1.3 Establish a robust cancer control monitoring and benchmarking system to drive optimal care

Harmonised national reporting will address diverse end-user needs by answering priority questions and supporting cancer control research. To drive optimal care and ensure accurate national benchmarking, a consistent analysis and reporting process will be established across all states and territories, involving agreed methodology and indicators for core outcomes comparison.

A key challenge in national benchmarking of diagnosis, treatment and care indicators is ensuring high clinician engagement and trust in the analysis and reporting. This has been crucial to the success of work in NSW, Queensland and other jurisdictions, and remains a requirement for broader implementation.

Short-term actions

1.1.1 Develop communication strategies for informing First Nations people what data are held relating to their interests, how the data is used and how the data can be accessed. This may include:

- partnering with First Nations communities to understand their information needs and priorities and to ensure data is described in a culturally relevant way (easy to use, interpret and digest)
- engaging with Aboriginal and Torres Strait Islander organisations and communities to be instructed about how the data should be accessed, managed, used, contextualised and reported.

1.2.1 Understand the current level of consumer data literacy related to improving health outcomes and the use of data in Australia, with a focus on priority population groups.

1.2.2 Review best practices for public engagement in data release, open access and public reporting and co-design nationally accessible materials and communication strategies on health and cancer data collection and use.

1.3.1 Establish a National Cancer Control Performance Reporting Framework that:

- leverages existing frameworks and identifies new key indicators for cancer control, including adherence to Optimal Care Pathways
- establishes a technical and clinical working group to define core indicators and data requirements
- implements cross-jurisdictional benchmarking and develops a process for transitioning from confidential to public reporting
- standardises data definitions and reporting indicators, by building on existing agreed definitions and indicators, with a focus on priority populations
- tests a national harmonised approach for reporting on two to three priority cancer control indicators across two Optimal Care Pathways.

Long-term actions

1.2.3 Implement public education and health data literacy measures to enhance trust and engagement in cancer data usage, explaining how data is collected, analysed, safeguarded and reported while empowering consumers to interpret and utilise this information effectively.

1.2.4 Develop and publish accessible cancer data reports that present meaningful information to help individuals make informed decisions about their treatment and care and about participation in research, including key performance indicators and benchmarks across jurisdictions.

1.3.2 Report on cancers across the Optimal Care Pathways across all jurisdictions.

Strategic Objective 2: A sustainable and fit-for-purpose data system

> *Foster a sustainable and fit-for-purpose data system that enables the timely collection of our health and population data inclusive of cancer and non-cancer data, collected across the ecosystem using nationally consistent standards to facilitate system interoperability and greater information exchange across the continuum of care and across jurisdictions.*

This objective aims to create an integrated and advanced data ecosystem underpinned by multiple interrelated assets. These assets will feed into the ecosystem to create a robust, cohesive data system ensuring timely, accurate and standardised data collection across the cancer continuum, fostering interoperability and enhancing health and population data utility. This objective also aims to enable analysis of outcomes for priority groups and the broader population, and service benchmarking across the cancer data ecosystem.

Importance

Adopting best practices in data collection will reduce fragmentation and duplication, improve quality and enhance timeliness of data capture, release and reporting, aligning with national policies and agreements. For First Nations communities, these practices must align with Indigenous Data Sovereignty principles to meet unique health data needs and community priorities.

A harmonised approach to data capture, storage and access will increase the cancer control sector's capacity to use emerging technologies and improve data interoperability across holdings.

Advancing cancer data collection and integration will enhance Australia's ability to answer crucial questions about cancer incidence, mortality, practice variations, outcome disparities and resource use. Taking guidance from Indigenous Data Sovereignty principles will ensure data reflects First Nations health experiences and needs. Addressing data gaps for priority populations will improve understanding of cancer prevalence and mortality rates across different locations and support continuous quality improvement and service design efforts.

Integrating cancer data within the broader health landscape and digital health infrastructure will leverage existing clinical and non-clinical assets to examine performance at multiple levels. Establishing population data as the foundation will mirror successful approaches like the NHDH. Over time, enhanced data availability will provide more precise insights into national health trends, benefiting from patient perspectives and addressing equity considerations for priority populations.

Current challenge

The cancer data ecosystem is fragmented, with important data scattered across various public and private data assets using inconsistent data definitions. This lack of a unified data system, combined with poorly defined roles, leads to duplication and data gaps, particularly affecting First Nations communities and other priority groups. The absence of common infrastructure and system interoperability further compounds these challenges.

Developing a mature data system that enables appropriate linkage or federated approaches across these holdings is critical. Enabling Indigenous Data Governance in this process will enhance trust and data utility for First Nations communities.

Work is underway to embed representation into governance of datasets; however, there is a risk of overburdening the sector with duplicative governance arrangements. Consideration needs to be given to building First Nations data governance leadership capacity in the sector to lead governance of First Nations data.

Overcoming barriers such as the lack of structured clinical reporting and inadequate data management support is essential for effective data access. This will provide a more comprehensive view of the cancer continuum and enable better-targeted improvements in patient outcomes. While challenging, implementing structured clinical reporting at the point of service delivery is essential for capturing currently unavailable data such as stage, treatment, and prognostic factors, including genomic data. A structured reporting approach will significantly enhance data integrity and utility.

Strengthening foundations for growth

Population-based cancer registries exist in all jurisdictions and form the core of the cancer data ecosystem. Some registries have innovated with enhanced e-path extraction, radiology data capture, and stage and treatment data collection from digital health systems such as electronic medical records (EMRs) and radiology information systems (RISs). Integrating these innovations with appropriate governance of Indigenous data can ensure culturally appropriate practices beneficial to First Nations communities.

Australia's growing network of clinical quality cancer registries has engaged clinicians in improving diagnosis and treatment quality for several cancers. Several innovative large data assets have also been developed as research initiatives that demonstrate safe integration of data from multiple sources.

These innovations demonstrate the potential for a harmonised approach to creating a sustainable, fit-for-purpose data ecosystem. Leveraging existing national strategies such as the National Digital Health Blueprint (2023–2033),[9] the National Digital Health Strategy (2023–2028)[8] and the Health Information Exchange[28] will ensure alignment with whole-of-government initiatives and allow faster implementation by building on existing structures.

This would provide a comprehensive view of patient, clinical, population and health service data, alongside broader health determinants, research insights, clinical trials, and emerging data streams like ambulatory care, genomics and radiomics.

To enhance interoperability and utility of cancer data, the Data Framework emphasises aligning with international datasets where relevant and achievable. For example, cancer registries already use the International Classification of

Diseases for Oncology (ICD-O) to classify the site, morphology, behaviour and grading of neoplasms, ensuring that data are comparable internationally.

Addressing key data gaps and improving data quality, particularly for First Nations communities, is crucial for effective monitoring of population-level changes, identifying disparities in cancer outcomes, and guiding targeted cancer-control strategies.

Implementation priorities and actions

2.1 Embed and implement the governance of First Nations data in the cancer data ecosystem

Embedding strong governance of First Nations data within the cancer data ecosystem is crucial for upholding and mobilising Indigenous Data Sovereignty and improving cancer outcomes for First Nations communities. This approach requires partnering with Indigenous people throughout the entire data lifecycle and ensuring their perspectives inform data governance decisions, as well as building the capacity of the sector to lead this approach.

Establishing First Nations data champions and enhancing data literacy within these communities are essential steps. Additionally, the cancer care sector must focus on cultural and organisational changes to prioritise First Nations involvement in decision-making regarding First Nations data. By providing accessible cancer data and fostering local accountability, we can create a more inclusive system that encourages meaningful participation from Indigenous peoples. This approach not only respects Indigenous Data Sovereignty but also contributes to more effective and culturally appropriate cancer care strategies.

2.2 Improve the timeliness of cancer data collection and reporting

Australia's cancer data in the Australian Cancer Database is typically available several years after diagnosis, which is insufficient for timely national surveillance of early outcomes of services. It also limits broader service performance monitoring. Despite advancements in digital health systems, automated reporting systems and AI technologies, many health facilities still rely on manual processes for data management.

Improving timeliness requires streamlining data entry, enhancing digital health systems, training healthcare staff, allocating sufficient resources, establishing clear guidelines, and developing efficient validation infrastructure. The aim is to provide data that supports timely clinical decision-making and health service evaluation for improving outcomes at both local and national levels. This is crucial for responsive and efficient cancer care management across Australia.

2.3 Strengthen existing mechanisms to ensure consistent and valid collection of key cancer data within Australian cancer registries

Population-based cancer registries are a critical component of Australia's data ecosystem. Initially established under jurisdictional public health legislation to report cancer incidence, their role has evolved to become a key foundation for integrated data assets. This evolution has led some registries to expand their data collection to include stage at diagnosis, broader pathology data, radiology information and treatment details.

However, this development has resulted in variability across registries in terms of data capture and definitions. There is now significant diversity in the roles, resources and capacities of both population-based cancer registries and clinical quality registries in Australia.

As Australia moves towards a harmonised national approach to creating integrated data assets, it is essential to clearly define and adequately resource the role of population-based cancer registries and clinical quality registries to ensure their important contribution to the data ecosystem. Additionally, exploring how these cancer registries can support each other's functions and align with digital health standardised terminology to enhance the understanding of cancer across Australia will be important. This collaboration will improve efficiency across registries, facilitating application of the principle that data is collected once but utilised for multiple purposes.

2.4 Advance the collection of cancer stage at diagnosis data as a key measure of equity and cancer control

Cancer stage is a key variable for understanding variations in cancer outcomes. It plays an integral role in assessing the success of screening and early diagnosis initiatives, evaluating treatment appropriateness and exploring outcome variations across populations. Assessing cancer stage at diagnosis is particularly important for initiatives aimed at improving outcomes for Aboriginal and Torres Strait Islander people and other priority population groups.

At population-based registry level, collecting stage data is resource intensive. While suitable for analysing whole-population trends, registry staging is not intended for assessment of treatment appropriateness at individual person level. A key limitation in relation to registries collecting population-level stage at diagnosis data is that certain relevant information, such as radiology reports, is currently not routinely provided to registries.

A report by the Australasian Association of Cancer Registries, commissioned by Cancer Australia, on national stage at diagnosis collection recommended prioritising stage data collection within health service data systems.[29] This approach would allow for easier extraction into cancer registries and other data systems. Several jurisdictions are currently exploring barriers to and enablers of stage collection and extraction to inform future work. There are also ongoing efforts to collect cancer stage data within clinical quality registries.

2.5 Agree and prioritise action on national data gaps

Comprehensive reporting on national cancer indicators is hindered by existing data gaps, variations in availability, and incomplete information along the cancer care continuum. This issue is particularly pronounced for certain tumour types, including rare and less common cancers.

In addition to the gaps in data regarding cancer stage at diagnosis, several other critical areas lack consistent or systematic collection across the country. These areas include metrics that support optimal and equitable care, patient experience data, quality of care indicators, First Nations identification, equity determinants for priority population groups, and non-stage prognostic indicators. Furthermore, there is insufficient data on the burden of non-melanoma skin cancers within the Australian population, in addition to data on genomics, radiomics and longer-term outcomes such as disease progression and recurrence by treatment type, treatment plans, received treatments, treatment locations and comorbidities.

Identifying and prioritising these data gaps is a crucial step toward enhancing existing data and generating new insights. This process is essential for improving health service utilisation and ultimately achieving better cancer outcomes across Australia.

2.6 Collect standardised national cancer data to support reporting on priority needs, including optimal cancer treatment and care, equity and patient outcomes and experiences

Consistent national reporting of key cancer data is fundamental to achieving the 10-year ambition of a modern, fit-for-purpose cancer control infrastructure, advanced by innovative application of technology, research and data.

Leveraging existing initiatives such as the NCCI and AHPF into a comprehensive national reporting framework represents a significant step towards achieving this goal. The NCCI currently provides a valuable foundation for reporting indicators and measures across the cancer care continuum, sourcing data from numerous collections. However, to fully realise its potential as the primary national reporting framework, several enhancements are necessary.

Efforts must be made to address existing data gaps within the NCCI. By identifying and filling these gaps, we can ensure a more comprehensive view of cancer control across Australia. This process will involve standardising data collections where relevant and expanding the scope of data sources.

The reporting framework should be expanded to incorporate additional quality indicators that measure the implementation of Optimal Care Pathways in services. These indicators will provide crucial insights into the effectiveness of cancer care delivery and help identify areas for improvement.

The development of nationally agreed core data specifications will be essential to support the NCCI's evolution. These specifications will provide foundational data for improving accessibility, consistency and comprehensiveness of cancer data for national reporting.

To ensure a comprehensive view of cancer across Australia, agreeing on and prioritising national questions is fundamental. The Australian Cancer Plan emphasises the necessity to address data gaps that impact the ability to assess optimal care provision at a population level and implications for improving cancer outcomes, as well as identifying specific data needs of end users across the complete cancer continuum. The prioritisation of data gaps would enable a focus on their respective importance and utility in addressing key questions. When data is collected across more than one asset, it is essential to ensure standardisation of data definitions, collection protocols, and quality control measures to maintain consistency and comparability in national reporting, including efforts to support comprehensive reporting of longer-term outcomes of cancer clinical trials. The core set of nationally agreed indicators should be reviewed in line with enhancements to the Optimal Care Pathways, to ensure any improvements to optimal care through new technologies and the like can be captured in the reporting framework.

2.7 Enhance the capture of structured pathology and radiology reporting for consistent data capture from source systems

Obtaining ready-to-use source data from digital health systems will significantly benefit cancer databases. Structured reporting enables automated data extraction, particularly from pathology and radiology, which are key cancer data sources. This approach aligns with a growing global consensus.

Structured pathology reports can provide several advantages by supporting automated cancer extraction and use in enhancing treatment planning and research. The Royal College of Pathologists of Australia publishes structured pathology reporting protocols for various cancers; however, there is much variability in their uptake and use in automated flow of data into cancer registries.

In radiology, the Royal Australian and New Zealand College of Radiologists is promoting structured reporting and exploring AI solutions to enhance the quality and timeliness of reporting. Notably, structured radiology reporting is less commonly utilised, and radiology reports do not routinely flow to cancer registries, due to both policy and implementation challenges. The Queensland Cancer Registry is currently exploring the automated flow of radiology reports to support stage capture and to monitor recurrence and disease progression. The large volume of images presents a challenge, highlighting the need for AI solutions to facilitate the flow and interpretation of the most relevant images. This automated approach saves time, reduces human error, and allows for more consistent and objective image interpretation across large volumes of visual data.

2.8 Explore the potential for structured clinical reporting of key data items within digital health systems

In addition to stage at diagnosis, various treatment and clinical variables are relevant for assessing prognosis, assessing adherence to Optimal Care Pathways, and evaluating treatment appropriateness. As Australia shifts to electronic capture of medical information, there is an opportunity to implement structured collection of key variables that can be extracted into broader data holdings.

Exploring the potential for structured clinical reporting of key data items within digital health systems such as EMRs requires leveraging existing successful models and frameworks but also significant cultural change and clinical engagement for success.

Short-term actions

2.1.1 Enhance First Nations community data capabilities and partnerships throughout the data lifecycle. This may include:

- leveraging relevant guidance from state and territory data governance groups
- strengthening existing First Nations data groups or establishing new ones as needed, acknowledging that governance of Indigenous data is not prescriptive
- identifying data-ready communities to collaborate with and engage across the data lifecycle
- building sector capacity to enable data sharing and support Indigenous Data Sovereignty
- applying the OCCAAARS (ownership, control, custodianship, accessibility, accountability, amplifying First Nations, relevant, sustainability) framework, focusing on accountability and amplifying community voices
- developing and using a culturally relevant and accurate data dictionary specific to First Nations communities to standardise data collection (to the extent feasible) and reporting, ensuring it is culturally relevant and accurate and reflects First Nations knowledges
- establishing First Nations communities' data champions across the cancer control sector to drive implementation of this Data Framework
- ensuring protective data practices that safeguard individual and collective interests, prioritising ethics and active community engagement
- partnering with First Nations communities at all stages of the data lifecycle to reflect priorities in community data.

2.1.2 Build towards organisational and cultural change to improve the capability of the sector and support inclusion of Aboriginal and Torres Strait Islander people in data governance. This may include:

- creating internal information resources, based on national guidance, to increase understanding of Indigenous Data Sovereignty within each individual organisation
- convening communities of practice related to data, which should incorporate consideration of this Data Framework into their terms of reference to embed a culture of best practice and knowledge sharing for governance of First Nations data among staff
- enacting Priority Reform Three under Closing the Gap: Transforming Government Organisations
- ensuring governance structures include First Nations peoples in the governance of First Nations data

2.2.1 Improve the timeliness of cancer data collection and reporting by:

- mapping the current state of timeliness of cancer incidence data and other priorities identified and issues impacting data timeliness for each jurisdiction
- outlining potential steps and resources required for improvements
- prioritising critical data items and exploring options for interoperability.

2.3.1 Address how the population-based cancer registries and clinical quality registries can support each other's roles and together extend the quality and depth of clinical data at the population level for greater completeness of the cancer data ecosystem.

2.3.2 Define the role of the Australian Cancer Data Alliance, including representation of the Australasian Association of Cancer Registries, in ensuring consistent cancer data collection across the data ecosystem.

2.3.3 Explore any potential for establishing a common cancer registry software platform that would enable greater levels of technical cooperation across all jurisdictions in Australia and support linkage of integrated data for people affected by cancer who cross borders for treatment.

2.4.1 Establish a cross-jurisdictional working group incorporating representation from population-based registries and clinical quality registries and clinical informatics, to explore the barriers and enablers of standardised stage collection in clinical workflows.

2.4.2 Form a demonstration project on the capture and extraction of stage at diagnosis, initially for two to three agreed cancer types, building on investment in breast cancer stage collection.

2.5.1 Establish a set of core indicators to assess adherence to the Optimal Care Pathways for inclusion in a National Cancer Control Performance Reporting Framework and define the data items needed to measure these and identify priority data gaps. This may include:

- undertaking a stocktake of existing projects measuring adherence to Optimal Care Pathways
- establishing a technical and clinical working group to define core indicators, and expanding on the National Cancer Control Indicators, to assess adherence to Optimal Care Pathways (tumour stream agnostic) for a National Cancer Control Performance Reporting Framework
- defining the data items needed to measure these indicators and identify the priority data gaps. This work will build on and link to work already underway on the Optimal Care Pathways Framework development.

2.5.2 Develop an agreed definition of key non-cancer variables linked to variations in cancer outcomes and a plan for their routine collection and integration in data assets at:

- patient level (e.g. performance status and comorbidities and social determinants of health)
- service level (e.g. service volume).

2.5.3 Develop an agreed priority list of non-stage related prognostic factors and test their collection within clinical and population-level information systems to support data extraction for analysis.

2.5.4 Define appropriate collection of nationally consistent patient-reported outcomes and experiences (PROMS and PREMS) for various levels of capture:

- Point of care measures to guide clinical encounters
- PROMS and PREMS for Aboriginal and Torres Strait Islander peoples and other priority populations
- Service-level measures to inform resourcing
- Population-level measures to inform understanding of factors influencing treatment completion, hospitalisation, and morbidity and mortality outcomes.

2.5.5 Establish priorities related to the collection and standardisation of genomic data for incorporation in population-based cancer registries.

- Include non-stage prognostic indicators (e.g. biomarkers).

2.6.1 Build on the National Cancer Control Indicators (NCCI) and national leadership by the Australian Institute of Health and Welfare and the Australian Bureau of Statistics, in collaboration with the Australasian Association of Cancer Registries, to develop and implement standardised nationally consistent, comparable and timely data to the extent feasible, collected across the cancer continuum, that can inform the NCCI. This data will be linkable to other health and health-relevant data (e.g. Person Level Integrated Data Asset) to provide a comprehensive sociodemographic picture of cancer in Australia and drive improved health system performance.

2.6.2 Standardise national datasets with agreed data definitions and formats, where feasible, to minimise discrepancies in data capture across platforms, jurisdictions and health sectors (e.g. primary care, public or private).

2.6.3 Establish a process engaging all stakeholders across the cancer sector to prioritise data gaps, focusing on their importance and utility in addressing key questions and identifying specific data needs of end users across the cancer continuum. This should include a mechanism for identifying new gaps as new technologies arise.

- Include community advocates from priority groups to enable the identification of research areas that align with community needs.

2.6.4 Define a set of core indicators to assess adherence to Optimal Care Pathways. Conduct a demonstration project with a small number of priority indicators for Optimal Care Pathways that can then be used to progress the next set of indicators.

2.7.1 Support the implementation of a standardised approach to electronic pathology data flow into cancer registries.

2.7.2 Work with the Royal College of Pathologists of Australasia and the Royal Australian and New Zealand College of Radiologists to build on work underway to address the barriers and enablers of structured pathology and radiology reporting for cancer. Develop an action plan for the implementation of level 6 structured pathology reporting and explore the utility of radiology data flow into cancer registries.

2.8.1 Examine current initiatives in extracting treatment data from oncology medical information systems (systemic therapy and radiotherapy) and develop a national action plan for implementation of national treatment data capture in all jurisdictions. This may include investigation of policy, regulation, legislation, funding and consumer and workforce health literacy as barriers to implementation.

2.8.2 Form a working group comprising digital health system implementation leads, clinicians, technical experts, and other stakeholders. This group will identify and agree on the key data items to be recorded in a structured way, starting with cancer stage. The group will also determine the best model to achieve this, define the barriers and enablers for implementation, and develop a pilot proof-of-concept approach as an initial step.

Long-term actions

2.1.3 Strengthen First Nations community data capabilities and partnerships throughout the data lifecycle. This may include:

- building data literacy, supported by tools specifically developed by Lowitja Institute
- supporting the development of data infrastructure for First Nations peoples
- supporting data training for First Nations people in the cancer sector
- developing partnership arrangements between First Nations community stakeholders and government agencies to facilitate agreed regular systematic data sharing.

2.1.4 Build towards organisational and cultural change within the cancer care sector to support the inclusion of Aboriginal and Torres Strait Islander people in data governance. This may include:

- ensuring the control of data ecosystems overseen by First Nations communities, grounded in traditional governance, practices and knowledge
- ensuring contextual and disaggregated data is accessible at individual and community levels
- ensuring datasets are co-created with First Nations peoples and communities
- engaging with or developing First Nations data governance groups.

2.2.2 Implement the necessary changes identified to improve timeliness of national cancer incidence data.

2.3.4 Develop a mechanism to monitor data consistency across the Australian cancer data ecosystem.

- Implementing unified standards (to the extent feasible) and regular audits will ensure accurate and consistent cancer data across Australia's ecosystem.

2.4.3 Routine collection of stage at diagnosis for all cancers within electronic information systems.

2.5.6 Validate patient-reported outcomes and experiences (PROMS and PREMS) measures and collection approaches for First Nations peoples and for other priority populations.

2.5.7 Establish a national approach to assessing the effectiveness of early detection (screening programs) on cancer outcomes and experiences and the long-term outcomes from cancer (mortality and morbidity) that incorporates alignment with the Optimal Care Pathways.

2.7.3 Identify leading pathologists who are adopting level 6 structured pathology reporting and leading radiologists who are adopting structured radiology reporting. Expand structured reporting training in educational programs to support the highest level of adoption.

2.7.4 Plan for the capture of recurrence and disease progression from radiology and pathology reports, and establish a national approach to incorporating radiology data into cancer registries, particularly for monitoring recurrence/progression, while considering legislative differences across jurisdictions.

2.7.5 Implement level 6 structured pathology reporting for agreed priority cancers.

2.8.3 Pilot the collection of agreed structured clinical reporting data for a range of cancers (including haematologic and paediatric).

Strategic Objective 3: User-centred, integrated and accessible data

> *Deliver a user-centred, integrated and accessible data system that incorporates longitudinal data to track changes over time, through the timely, streamlined and safe promotion of trusted, transparent and advanced data-sharing arrangements using integrated data assets at national and jurisdictional levels.*

Importance

Effective data integration and interoperability across systems and datasets are crucial for achieving the Data Framework's goals. Linking cancer data with other health and routinely collected person-level data, including clinical quality registries and research datasets, and relevant routinely collected administrative data will provide comprehensive patient outcome insights to inform improvements.

For priority populations, this integration must be undertaken in an ethical way to ensure key benefits are focused on First Nations peoples, culturally and linguistically diverse communities, people living with disability, and those in rural and remote areas.

Simplifying data access and improving data timeliness will encourage greater data utilisation, leading to improved assessment of cancer care and outcomes and increased opportunities for system enhancements. Prioritising collaboration and openness across government, as inherent values of public data custodianship, is key to reducing integration barriers and simplifying access for all end users. This includes establishing formal data-sharing agreements and traditional knowledge labels to protect and explain First Nations data.

Ongoing communication between data users and custodians regarding data use, analysis outputs, and project governance is essential. These communications, underpinned by strong governance principles, will serve as a risk management tool and help identify additional barriers to addressing common data requests and needs.

Current challenge

The current data governance system is complex, with multiple custodians, multi-layer ethics approvals, and duplicative access processes leading to high costs and delays for linked data. This complexity particularly hinders First Nations communities' data access and utilisation.

Without effective data linkage, there is insufficient information on priority populations, limiting our understanding of their specific cancer experiences and outcomes. This gap hinders the development of targeted interventions and policies to address health disparities. Furthermore, establishing linkage and associated business rules requires significant resources, including skilled personnel to perform the complex work of data integration and management.

Ensuring enduring data linkages and research overseen by appropriate Aboriginal and Torres Strait Islander ethical practices is crucial to overcoming these barriers. A robust solution is needed to streamline and expedite data access while upholding standards.

To increase and enhance our evidence base, particularly for rare cancers where Australian data may be limited by cohort size, there is a need to connect with international research. International data sharing presents challenges – particularly concerning unit record data and privacy. Solutions need to be identified which enable overseas researchers to access Australian cancer data while adequately protecting Australians' privacy.

An improved system should establish enduring linked data collections with streamlined governance, simplifying access for users while ensuring data safety, transparency, accountability and ethical standards. This necessitates fit-for-purpose models, potentially including a federated data infrastructure facilitating a 'link once, use many times' approach.

Strengthening foundations for growth

National initiatives like the NHDH can serve as blueprints for enduring data linkage assets. Attaching a cancer module to the NHDH will create a usable asset for exploring cancer outcomes, potentially including jurisdictional collections. The NHDH's strength lies in its integration with datasets like the Australian Cancer Database and PLIDA, allowing examination of unwarranted variations and better understanding of cancer care and outcomes for priority groups and of the impact of the social determinants of health.

Nationally the DATA Scheme, managed by the Office of the National Data Commissioner under the *Data Availability and Transparency Act 2022*, aims to streamline accreditation and sharing of national datasets across government bodies and universities. Other national initiatives, such as the Health Information Exchange and eRequesting, aim to streamline the transfer of data between systems.

At the jurisdictional level, initiatives like the Enduring Cancer Data Linkage (CanDLe) program (NSW and ACT) feature overarching ethics approval for system performance reporting, researcher accreditation processes, and communities of practice to build capacity and reduce duplication. Integrating governance of First Nations data principles into these initiatives can ensure culturally appropriate practices beneficial to First Nations communities.

These approaches reduce burden on data users, increase work volume and quality, and shift focus from process to outcomes in performance monitoring and improvement efforts.

Implementation priorities and actions

3.1 Ensure enduring data linkages and associated access, as well as research, is overseen with appropriate Aboriginal and Torres Strait Islander ethical practices

Enduring data linkages and open data access must adhere to Aboriginal and Torres Strait Islander ethical practices, ensuring research aligns with First Nations communities' aspirations and respects their data sovereignty.

Formal data-sharing agreements, traditional knowledge labels, and clear identifier parameters protect First Nations data. Implementing Indigenous Data Governance within linked datasets and robust linkage protocols ensures comprehensive and respectful data collection.

Ethical practices must prioritise First Nations rights at all stages, including developing accessible methods for communities to understand and access relevant data. Reviewing policies hindering data sharing aligns with Closing the Gap goals, empowering First Nations-driven development.

Organisational and cultural change in the public sector is essential to include First Nations people in data governance. Ethical research conduct and accountable data structures are paramount. Cancer Australia-funded projects should have appropriate controls over secondary data use, aligning with Medical Research Future Fund and National Health and Medical Research Council ethical requirements.

Applying CARE (collective benefit, authority to control, responsibility, ethics) and FAIR (findable, accessible, interoperable, reusable) principles ensures open and accessible cancer datasets with appropriate cultural governance. While FAIR principles facilitate data sharing and reuse, CARE principles complement them by ensuring ethical data use and advancing First Nations innovation and self-determination.

3.2 Enhance data access through effective and efficient data governance and streamlined ethics approvals

Streamlining and harmonising data governance across states and territories is essential to enhance data access while maintaining security. This will ensure timely, secure data sharing among healthcare providers, researchers and policymakers, improving care provision, research capabilities and informed decision-making.

Data governance will cover policies promoting data availability, accessibility, quality and security. Data custodians will be responsible for dataset management. The Five Safes framework provides a mechanism for data custodians to take necessary and reasonable steps to manage disclosure risk in their data releases.[30]

Prioritising streamlined data custodian approvals over ethics alone is crucial. Standardising these processes will simplify and expedite data access. Simplifying legal, ethical and compliance processes will remove current system constraints and improve affordability of data access.

Consideration needs to be given to funding models for national data assets to ensure affordability of access and long-term sustainability and accessibility of the data system. Developing a nationally consistent approach to consent waivers, in collaboration with consumers, is necessary. Implementing a carefully managed opt-out consent process is crucial for public trust. Clinicians play a key role in informing patients about data usage, with clear guidance on when opt-in or opt-out consent is required.

Implementation of these actions will be considered, noting that some initiatives are already in place.

3.3 Adopt a harmonised approach to enduring integrated data assets that safely enable rapid access by accredited end users, while ensuring data safety, quality and reliability

Data access approaches are evolving from project-specific approvals to enduring linked data assets with multiple users. These assets will enhance data access and return on investment while ensuring data safety. National adherence to the FHIR (Fast Healthcare Interoperability Resources) standard will enable interoperability across the data ecosystem.

Models like the NHDH can serve as a blueprint for enduring data linkage assets. Attaching a cancer spine to the NHDH will create a usable asset for exploring cancer outcomes, potentially including jurisdictional collections.

Integrating clinical trial and research data into these assets is crucial, where possible supporting the ‘collect once, share and use multiple times’ model. This will enhance collaboration, promote data reuse and accelerate research innovation.

Monitoring data quality and performance is fundamental for reliability. Involving consumers in quality assessment can build public trust. Robust security and privacy measures are crucial for maintaining data integrity. Linking cancer data with other datasets will provide a comprehensive view of outcomes for patient groups, requiring quality analytic tools.

Once established, the focus will shift from asset creation to enabling access, with successful use approaches already demonstrated in various jurisdictions.

Short-term actions

3.1.1 Apply the CARE and FAIR principles to First Nations cancer research and data linkage. This may include:

- ensuring Indigenous Data Sovereignty principles are integrated into the development of linked datasets, respecting the rights and interests of First Nations communities
- establishing clear parameters around identifiers, particularly for Aboriginal and Torres Strait Islander people, to ensure their data are accurately represented and protected
- implementing robust data linkage protocols that respect Indigenous Data Sovereignty principles, providing a comprehensive and respectful view of patient information
- ensuring strong First Nations governance and leadership of linked data assets.

3.1.2 Develop communication strategies for informing First Nations people what data are held relating to their interests, how the data is used and how it can be accessed. This may include:

- reviewing and updating existing data governance policies and frameworks to align with this Data Framework
- developing an Aboriginal and Torres Strait Islander data catalogue which would provide data requesters with an easier path to locate the relevant data assets and request access
- publishing data access protocols, ensuring promotion to Aboriginal and Torres Strait Islander people and communities
- reviewing policies and legislation that are barriers to data sharing at a disaggregated level
- facilitating a culture of data sharing to achieve the aims of Priority Reform Four of Closing the Gap.

3.2.1 Align with ongoing efforts to harmonise data access and approval approaches and processes across jurisdictions, including for linked data assets, and monitor progress (potentially overseen by a jurisdictional/national committee).

3.3.1 Create a comprehensive data blueprint for cancer data assets in Australia that leverages the Australian Core Data for Interoperability (AUCDI) Sparked program and National Health Data Hub models.

3.3.2 Develop a collaboration of national data custodians to define a harmonised approach to data flow into the jurisdictional and national data assets and processes to maintain currency. This will include streamlined legal, ethical and compliance processes through mutual recognition and other means to facilitate timely data access.

3.3.3 Develop a nationally agreed accredited user model and mechanisms to monitor its impact on data use and data security.

3.3.4 Work with the Australian Government to establish a mechanism to trial a model for data subsets incorporating key research, clinical trials and biobank datasets.

Long-term actions

3.1.3 Apply the CARE and FAIR principles to First Nations cancer research and data linkage. This may include:

- ensuring data ecosystems are designed and function in ways that enable First Nations peoples to derive collective benefit from the data
- supporting First Nations governance structures to develop data governance policies and practices
- ensuring potential data risks are mitigated for First Nations communities
- ensuring ethical access and use of cancer data
- ensuring accountable data structures exist and ensuring data practices are transparent, responsible and accountable
- developing formal data-sharing agreements where appropriate.

3.1.4 Shift from dominant deficit discourses (e.g. BADDR data – blaming, aggregate, decontextualised, deficit, restricted) in data collection and reporting, to position First Nations communities to develop strength-based and culturally appropriate datasets.

3.2.2 Expand harmonised and simplified data access systems across all jurisdictions.

3.3.5 Implement a nationally agreed accredited user data access approach with transparent public reporting about its effectiveness.

Enablers

The enablers are the building blocks underpinning the Data Framework's success and are essential to achieving its goal. These enablers will be shaped by the collective efforts of the cancer sector, integrating with the broader national context and complemented by collaboration between jurisdictions and the sector.

Achieving the strategic objectives requires whole-of-sector resourcing commitments and responsibility to take and enable action.

Culture change

A shift in the culture surrounding data use and management is essential to success.

Viewing cancer data as an asset to leverage for improved cancer control requires transparent communication and public trust. Clinicians and stakeholders across primary care, public and private sectors, need to understand and adopt efficient governance practices and structured reporting. Education and training programs empower effective data use, promoting a culture of data sharing and collaboration. This cultural shift ensures high-quality data collection and utilisation.

Technology and innovation

Technology and innovation are critical to enhancing how data is captured, stored, analysed, reported and shared across the system.

There are opportunities to capitalise on the evolving nature of AI and natural processing technologies, while also considering the associated risks. A harmonised approach leverages expanding technologies to align system processes across jurisdictions and the cancer control continuum. This enables timely data monitoring and automation, driving more efficient service delivery, clinical care and research. Technology has the potential to transform cancer data, but ensuing data security is maintained will be critical for ongoing use.

Data workforce capacity and capability

A skilled and capable data workforce is necessary to maximise the use of cancer data.

This includes roles in data collection (including at point of care), governance and analysis. Encouraging skill pooling across content areas overcomes the current siloing of data skills across teams, fostering an integrated workforce. Enhanced capacity ensures high-quality data management and analysis, providing the insights needed to inform practice and policy, thereby improving diagnosis, treatment, health service delivery and care.

Effective governance and standards

Effective data governance and management ensures efficient, safe and appropriate data use.

There are opportunities to standardise principles for data management, accreditation and use across jurisdictions, including leveraging existing governance frameworks and standards. Embedding accountability and monitoring the system's effectiveness enhances access. This drives improvements supporting the creation of a sustainable data ecosystem that informs service delivery and clinical care, leading to better cancer outcomes. Incorporation of Indigenous Data Sovereignty principles ensures Aboriginal and Torres Strait Islander people control the collection, use and storage of data about their communities

Implementation Roadmap

The Implementation Roadmap outlines short- and long-term priorities and actions that will require a whole-of-sector effort, including targeted strategies to address the needs of and actively involve priority populations. This roadmap is aligned with the 10-year timeframe of the Australian Cancer Plan, published in November 2023. Implementation priorities were determined through targeted consultation with stakeholders.

Implementation priorities and actions	
Short-term horizon (by 2029)	**Long-term horizon (by 2033)**
A mature performance reporting system	
1.1 Indigenous Data Sovereignty and Governance for improved First Nations community outcomes	
1.1.1 Develop communication strategies for informing First Nations people what data are held relating to their interests, how the data is used and how the data can be accessed	
1.2 Build and maintain public trust in the data system	
1.2.1 Understand the current level of consumer data literacy related to improving health outcomes and the use of data in Australia, with a focus on priority population groups **1.2.2** Review best practices for public engagement in data release, open access and public reporting and co-design nationally accessible materials and communication strategies on health and cancer data collection and use	**1.2.3** Implement public education and health data literacy measures to enhance trust and engagement in cancer data usage, explaining how data is collected, analysed, safeguarded and reported while empowering consumers to interpret and utilise this information effectively **1.2.4** Develop and publish accessible cancer data reports that present meaningful information to help individuals make informed decisions about their treatment and care and about participation in research, including key performance indicators and benchmarks across jurisdictions
1.3 Establish a robust cancer control monitoring and benchmarking system to drive optimal care	
1.3.1 Establish a National Cancer Control Performance Reporting Framework that: • leverages existing frameworks and identifies new key indicators for cancer control, including adherence to Optimal Care Pathways • establishes a technical and clinical working group to define core indicators and data requirements • implements cross-jurisdictional benchmarking and develops a process for transitioning from confidential to public reporting • standardises data definitions and reporting indicators, by building on existing agreed definitions and indicators, with a focus on priority populations • tests a national harmonised approach for reporting on two to three priority cancer control indicators across two Optimal Care Pathways	**1.3.2** Report on cancers across the Optimal Care Pathways across all jurisdictions

Implementation priorities and actions	
Short-term horizon (by 2029)	**Long-term horizon (by 2033)**
A sustainable and fit-for-purpose data system	
2.1 Embed and implement the governance of First Nations data in the cancer data ecosystem	
2.1.1 Enhance First Nations community data capabilities and partnerships throughout the data lifecycle **2.1.2** Build towards organisational and cultural change to improve the capability of the sector and support inclusion of Aboriginal and Torres Strait Islander people in data governance	**2.1.3** Strengthen First Nations community data capabilities and partnerships throughout the data lifecycle **2.1.4** Build towards organisational and cultural change within the cancer care sector to support the inclusion of Aboriginal and Torres Strait Islander people in data governance
2.2 Improve the timeliness of cancer data collection and reporting	
2.2.1 Improve the timeliness of cancer data collection and reporting by: • mapping the current state of timeliness of cancer incidence data and other priorities identified and issues impacting data timeliness for each jurisdiction • outlining potential steps and resources required for improvements • prioritising critical data items and exploring options for interoperability	**2.2.2** Implement the necessary changes identified to improve timeliness of national cancer incidence data
2.3 Strengthen existing mechanisms to ensure consistent and valid collection of key cancer data within Australian cancer registries	
2.3.1 Address how the population-based cancer registries and clinical quality registries can support each other’s roles and together extend the quality and depth of clinical data at the population level for greater completeness of the cancer data ecosystem **2.3.2** Define the role of the Australian Cancer Data Alliance, including representation of the Australasian Association of Cancer Registries, in ensuring consistent cancer data collection across the data ecosystem **2.3.3** Explore any potential for establishing a common cancer registry software platform that would enable greater levels of technical cooperation across all jurisdictions in Australia and support linkage of integrated data for people affected by cancer who cross borders for treatment	**2.3.4** Develop a mechanism to monitor data consistency across the Australian cancer data ecosystem

Implementation priorities and actions	
Short-term horizon (by 2029)	**Long-term horizon (by 2033)**
2.4 Advance the collection of cancer stage at diagnosis data as a key measure of equity and cancer control	
2.4.1 Establish a cross-jurisdictional working group incorporating representation from population-based registries and clinical quality registries and clinical informatics, to explore the barriers and enablers of standardised stage collection in clinical workflows **2.4.2** Form a demonstration project on the capture and extraction of stage at diagnosis, initially for two to three agreed cancer types, building on investment in breast cancer stage collection	**2.4.3** Routine collection of stage at diagnosis for all cancers within electronic information systems
2.5 Agree and prioritise action on national data gaps	
2.5.1 Establish a set of core indicators to assess adherence to the Optimal Care Pathways for inclusion in a National Cancer Control Performance Reporting Framework and define the data items needed to measure these and identify priority data gaps **2.5.2** Develop an agreed definition of key non-cancer variables linked to variations in cancer outcomes and a plan for their routine collection and integration in data assets **2.5.3** Develop an agreed priority list of non-stage related prognostic factors and test their collection within clinical and population-level information systems to support data extraction for analysis **2.5.4** Define appropriate collection of nationally consistent patient-reported outcomes and experiences (PROMS and PREMS) for various levels of capture **2.5.5** Establish priorities related to the collection and standardisation of genomic data for incorporation in population-based cancer registries	**2.5.6** Validate patient-reported outcomes and experiences (PROMS and PREMS) measures and collection approaches for First Nations peoples and for other priority populations **2.5.7** Establish a national approach to assessing the effects of early detection (screening programs) on cancer outcomes and experiences and on the long-term outcomes from cancer (mortality and morbidity) that incorporates alignment with the Optimal Care Pathways

Implementation priorities and actions	
Short-term horizon (by 2029)	**Long-term horizon (by 2033)**
2.6 Collect standardised national cancer data to support reporting on priority needs, including optimal cancer treatment and care, equity and patient outcomes and experiences	
2.6.1 Build on the National Cancer Control Indicators (NCCI) and national leadership by the Australian Institute of Health and Welfare and the Australian Bureau of Statistics, in collaboration with the Australasian Association of Cancer Registries, to develop and implement standardised nationally consistent, comparable and timely data to the extent feasible, collected across the cancer continuum, that can inform the NCCI. This data will be linkable to other health and health-relevant data (e.g. Person Level Integrated Data Asset) to provide a comprehensive sociodemographic picture of cancer in Australia and drive improved health system performance **2.6.2** Standardise national datasets with agreed data definitions and formats, where feasible, to minimise discrepancies in data capture across platforms, jurisdictions and health sectors (e.g. primary care, public or private) **2.6.3** Establish a process engaging all stakeholders across the cancer sector to prioritise data gaps, focusing on their importance and utility in addressing key questions and identifying specific data needs of end users across the cancer continuum. This should include a mechanism for identifying new gaps as new technologies arise **2.6.4** Define a set of core indicators to assess adherence to the Optimal Care Pathways. Conduct a demonstration project with a small number of priority indicators for Optimal Care Pathways that can then be used to progress the next set of indicators	

<table>
<tr><th colspan="2">Implementation priorities and actions</th></tr>
<tr><th>Short-term horizon (by 2029)</th><th>Long-term horizon (by 2033)</th></tr>
<tr><td colspan="2">2.7 Enhance the capture of structured pathology and radiology reporting for consistent data capture from source systems</td></tr>
<tr><td>2.7.1 Support the implementation of a standardised approach to electronic pathology data flow into cancer registries
2.7.2 Work with the Royal College of Pathologists of Australasia and the Royal Australian and New Zealand College of Radiologists to build on work underway to address the barriers and enablers of structured pathology and radiology reporting for cancer. Develop an action plan for the implementation of level 6 structured pathology reporting and explore the utility of radiology data flow into cancer registries</td><td>2.7.3 Identify leading pathologists who are adopting level 6 structured pathology reporting and leading radiologists who are adopting structured radiology reporting. Expand structured reporting training in educational programs to support the highest level of adoption
2.7.4 Plan for the capture of recurrence and disease progression from radiology and pathology reports, and establish a national approach to incorporating radiology data into cancer registries, particularly for monitoring recurrence/progression, while considering legislative differences across jurisdictions
2.7.5 Implement level 6 structured pathology reporting for agreed priority cancers</td></tr>
<tr><td colspan="2">2.8 Explore the potential for structured clinical reporting of key data items within digital health systems</td></tr>
<tr><td>2.8.1 Examine current initiatives in extracting treatment data from oncology medical information systems (systemic therapy and radiotherapy) and develop a national action plan for implementation of national treatment data capture in all jurisdictions. This may include investigation of policy, regulation, legislation, funding and consumer and workforce health literacy as barriers to implementation
2.8.2 Form a working group comprising digital health system implementation leads, clinicians, technical experts, and other stakeholders. This group will identify and agree on the key data items to be recorded in a structured way, starting with cancer stage. The group will also determine the best model to achieve this, define the barriers and enablers for implementation, and develop a pilot proof-of-concept approach as an initial step</td><td>2.8.3 Pilot the collection of agreed structured clinical reporting data for a range of cancers (including haematologic and paediatric)</td></tr>
</table>

Implementation priorities and actions	
Short-term horizon (by 2029)	**Long-term horizon (by 2033)**
User-centred, integrated and accessible data	
3.1 Ensure enduring data linkages and associated access, as well as research, is overseen with appropriate Aboriginal and Torres Strait Islander ethical practices	
3.1.1 Apply the CARE and FAIR principles to First Nations cancer research and data linkage **3.1.2** Develop communication strategies for informing First Nations people what data are held relating to their interests, how the data is used and how it can be accessed.	**3.1.3** Apply the CARE and FAIR principles to First Nations cancer research and data linkage **3.1.4** Shift from dominant deficit discourses (e.g. BADDR data – blaming, aggregate, decontextualised, deficit, restricted) in data collection and reporting, to position First Nations communities to develop strength-based and culturally appropriate datasets
3.2 Enhance data access through effective and efficient data governance and streamlined ethics approvals	
3.2.1 Align with ongoing efforts to harmonise data access and approval approaches and processes across jurisdictions, including for linked data assets, and monitor progress (potentially overseen by a jurisdictional/national committee)	**3.2.2** Expand harmonised and simplified data access systems across all jurisdictions
3.3 Adopt a harmonised approach to enduring integrated data assets that safely enable rapid access by accredited end users, while ensuring data safety, quality and reliability	
3.3.1 Create a comprehensive data blueprint for cancer data assets in Australia that leverage the Australian Core Data for Interoperability (AUCDI) Sparked program and National Health Data Hub models **3.3.2** Develop a collaboration of national data custodians to define a harmonised approach to data flow into the jurisdictional and national data assets and processes to maintain currency. This will include streamlined legal, ethical and compliance processes through mutual recognition and other means to facilitate timely data access **3.3.3** Develop a nationally agreed accredited user model and mechanisms to monitor its impact on data use and data security **3.3.4** Work with the Australian Government to establish a mechanism to trial a model for data subsets incorporating key research, clinical trials and biobank datasets	**3.3.5** Implement a nationally agreed accredited user data access approach with transparent public reporting about its effectiveness

Glossary

Term	Definition
Aboriginal community controlled health services (ACCHSs)	Non-government, not-for-profit primary health care services initiated and operated by the local Aboriginal community to deliver holistic, comprehensive and culturally responsive health care. ACCHSs are incorporated, based in an Aboriginal community, and governed by a majority Aboriginal board which the local community elects.
Ambulatory care	Ambulatory care refers to medical services performed on an outpatient basis, without admission to a hospital or other facility.
BADDR data	Defined by Walter (2018)[31] to describe the dominant deficit discourses within data about Aboriginal and Torres Strait Islander peoples: • Blaming data • Aggregate data • Decontextualised data • Deficit, government priority data • Restricted access data.
Cancer care continuum	A person's cancer experience and interactions with the health system, from prevention, early detection, initial presentation, diagnosis and treatment to survivorship and/or end-of-life care and long-term follow-up.
Cancer care sector	All parts of health and other systems relevant to cancer control, including people, services and organisations that contribute to cancer control, along the continuum from prevention to survivorship and/or end-of-life care and long-term follow-up. Cancer care is delivered through both public and private health systems by government and non-government providers.
Cancer control	Cancer control aims to reduce the incidence, morbidity and mortality of cancer and to improve the quality of life of cancer patients in a defined population, through the systematic implementation of evidence-based interventions for prevention, early detection, diagnosis, treatment and palliative care. Comprehensive cancer control addresses the whole population, while seeking to respond to the needs of the different subgroups at greater risk.
Cancer incidence	Number of new cancer cases occurring in a defined population in a defined period of time.
Clinical informatics	Technology and data analytics used to improve patient care outcomes, treatment and care.
Clinical quality registries	Clinical quality registries are structured systems that collect and analyse clinical data to monitor and improve the quality of care, facilitating benchmarking and evidence-based practice across the cancer care continuum.

Term	Definition
Co-design	Co-design brings professionals and end users together to design new services, resources and policies. Applied to policy, this can include empowering people affected by a policy issue to contribute to its solution. Co-design with Aboriginal and Torres Strait Islander people is fundamental to achieving change across the health system and to achieving better outcomes. Key principles and best practices for co-design in health with First Nations Australians include First Nations leadership, culturally grounded approach, respect, benefit to community, inclusive partnerships, and transparency and evaluation.
Comprehensive care	Comprehensive cancer care integrates cancer research, clinical trials, education and treatment, providing optimal care and support for people affected by cancer in all locations across the entire cancer continuum, and subsequent care monitoring in the longer term.
Consumer	Consumer is used to refer to a person affected by cancer as a patient, survivor, carer or family member; or a consumer organisation representing the views of consumers.
Cultural determinants of First Nations health	The cultural determinants of First Nations health are protective factors that support good health and wellbeing. Cultural determinants of health for Aboriginal and Torres Strait Islander people include: • connection to country • kinship • knowledge and beliefs • language • self-determination • cultural expression.
Data custodian	A data custodian is a person or entity responsible for managing and protecting an organisation's data. Data custodians work closely with data owners, users, IT staff, and compliance teams to ensure that data is managed, protected, and used properly.
Data driven	Utilising analysis and interpretation of comprehensive data to inform strategic decision-making.
Data governance	Data governance means setting internal standards and data policies that apply to how data is gathered, stored, processed and disposed of. It governs who can access different kinds of data and what kinds of data are under governance.
Data management	Data management is the practice of collecting, organising, managing and accessing data to support productivity, efficiency and decision-making.
Diagnosis, stage at diagnosis and treatment planning	This step outlines the process for confirming (or eliminating) a cancer diagnosis, stage of cancer, relevant biomarkers and a subsequent treatment plan. The guiding principle is that an appropriate multidisciplinary team should determine the treatment plan.

Term	Definition
Digital health systems	Digital systems used to by clinicians and staff to gather, manage and consult patient information and data to inform and record patient care in real time. electronic medical records, and radiology information systems are two kinds of digital health systems.
Ecosystem	A complex network or interconnected system, in this case referring to the interconnectedness of health and cancer data.
Electronic health record (EHR)	Electronic health records store your health information in a secure digital system. Australia's national system is called My Health Record.
Electronic medical record (EMR)	A system utilised day to day by clinicians and staff to gather, manage and consult patient information and data to inform and record patient care delivery in real time.
Equity	Health equity means all Australians are supported by our national systems in the ways most suited to their cultural, socioeconomic, geographic, environmental and personal situation to achieve the best possible cancer outcomes. The Australian Cancer Plan acknowledges that to achieve equity, some priority population groups need an additional and targeted focus and support. Equitable access to services is a further objective.
Fast Healthcare Interoperability Resources (FHIR)	The FHIR standard defines how healthcare information can be exchanged between different computer systems regardless of how it is stored in those systems.
First Nations data	First Nations data refers to information, in any format or medium, collected, analysed, stored and interpreted within the context of First Nations individuals, collectives, populations, entities, lifeways, cultures, knowledge systems, lands, biodiversity, water and other resources.
Genomics	Genomics is the study of genes and other genetic information, their functions, how they interact with each other and with the environment, and how certain diseases, such as cancer, form. This may lead to new ways to prevent, diagnose and treat cancer.
Health outcome	A health-related change due to a preventive or clinical or health service intervention. The intervention may be single or multiple, and the outcome may relate to a person, group or population, or be partly or wholly due to the intervention.
Health professionals	The health workforce in Australia is large and diverse, covering many occupations. These include health practitioners registered with the Australian Health Practitioner Regulation Agency, as well as other health professionals and health support workers.
Health services	Services that provide health care, treatment and support. This includes public, private and non-government services.
Hospital administration datasets	Hospital administration datasets encompass comprehensive data on treatment given in hospitals and on related patient demographics, patient care activities and other clinical interventions. This is crucial for administrative purposes such as resource management, policy development and compliance.

Term	Definition
Indigenous Data Governance	The process of establishing policies, practices and structures to give First Nations communities control over how First Nations data is collected, accessed, used and managed.
Indigenous Data Sovereignty	The right of Aboriginal and Torres Strait Islander peoples to govern the collection, ownership and application of information and knowledge about Indigenous communities, peoples, lands and resources.
Mature	Describes a stage where systems, processes and practices are fully developed, consistently applied and effectively used to achieve reliable and high-quality outcomes.
Metrics	Standards of measurement used for assessing and evaluating performance or outcomes.
Mortality	The death rate or the number of deaths in a certain group of people in a certain period of time.
Oncology	A branch of medicine that is focused on the prevention, diagnosis and treatment of cancer.
Optimal Care Pathways (OCPs)	The OCPs outline consistent, safe, high-quality and evidence-based care for people with cancer. They aim to improve patient outcomes by promoting quality cancer care and ensuring that all people diagnosed with cancer receive the best care, irrespective of where they live or receive cancer treatment. There are cancer-specific OCPs and population-specific OCPs. Seven key principles underpin the guidance provided in the OCPs: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research, clinical trials and service monitoring. These principles remain central to the delivery of quality care throughout the cancer continuum and always put patients at the centre of care. OCPs define seven steps in the cancer continuum. Each step outlines nationally agreed best practice to achieve high-quality cancer care: 1. Prevention and early detection 2. Presentation, initial investigations and referral 3. Diagnosis, staging and assessment of other prognostic indicators, and treatment planning 4. Treatment 5. Care after initial treatment and recovery 6. Managing recurrent, residual or metastatic disease 7. End-of-life care.
Population-based cancer registries	Population-based cancer registries systematically collect and maintain data on cancer incidence, types and outcomes within a defined population to support epidemiological research, healthcare planning and treatment.

Term	Definition
Primary care	Primary care usually refers to the first contact an individual with a health condition has with the health system. Primary health care covers hospital care and health care that is not related to a hospital visit, including health promotion, prevention, early intervention, treatment of acute conditions, and chronic condition management. Primary health care services are delivered in settings such as general practices, community health centres, allied health practices and Aboriginal community controlled health services, and via technologies such as telehealth and video consultations. Primary health care professionals include general practitioners, nurses, nurse practitioners, allied health professionals, midwives, pharmacists, dentists, and Aboriginal and Torres Strait Islander health workers and health practitioners.
Priority population groups	The Australian Cancer Plan identifies the following population groups as priorities for the delivery of nationally equitable outcomes in cancer control. • Aboriginal and Torres Strait Islander people • Adolescents and young adults • Children • People from culturally and linguistically diverse (CALD) backgrounds • People living with disability • Lesbian, gay, bisexual, transgender, intersex, queer, asexual, and other gender-diverse people (LGBTIQA+) • People in lower socioeconomic groups • People living with a mental illness • Older Australians • People living in rural and remote areas.
Radiology information system (RIS)	A RIS is a solution used to manage electronic medical records, imaging, and diagnostic data storage in radiology departments. It may include or exclude a picture archiving and communication system.
Radiomics	A field of research that uses medical images to extract quantitative data for diagnosis, treatment and monitoring. It involves analysing images to extract features that are difficult for the human eye to recognise or quantify.
Screening	An organised program (using tests, examinations, or other procedures) to identify diseases such as cancer, or changes which may later develop into disease such as cancer, before symptoms appear.
Social determinants of health	Determinants of health are non-medical sociodemographic factors that positively or negatively influence health outcomes. Social determinants of health are part of the wider determinants of health, which include the conditions in which people are born, grow, work, live, and age. Social determinants of health include family, housing, employment, working conditions, and social support and participation.

Term	Definition
Stakeholder	Any person, group or organisation that has a vital interest in cancer care or services.
Structured reporting	Structured reporting is the creation of standardised reports, usually based on centralised templates, which provide essential criteria and classifications standards, predominantly in a question-answer format, for optimal communication.
Sustainable	Describes a stage where systems, processes and practices can be maintained over time without extra resources or effort, ensuring they continue to work effectively into the future.
Treatment	This step includes the use of tailored therapies and medical interventions for managing and treating specific cancer types. This step also may encompass provision of training experiences and facilities required of treating clinicians and health services for providing optimal cancer care.
Veterans	Veterans are people who have any experience in the Australian Defence Force, including permanent, reserve and former (ex-serving) personnel.

Acronyms

Acronym	Phrase
AACR	Australasian Association of Cancer Registries
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AHPF	Australian Health Performance Framework
AI	Artificial intelligence
AIHW	Australian Institute of Health and Welfare
AUCDI	Australian Core Data for Interoperability
BADDR	Blaming, aggregate, decontextualised, deficit, restricted
CanDLe	Enduring Cancer Data Linkage
CARE	Collective benefit, authority to control, responsibility, ethics
DOHAC	Department of Health and Aged Care
EHR	Electronic health record
EMR	Electronic medical record
FAIR	Findable, accessible, interoperable, reusable
FHIR	Fast Healthcare Interoperability Resources
HPV	Human papillomavirus
IARC	International Agency for Research on Cancer
ICBP	International Cancer Benchmarking Partnership
LGBTIQA+	Lesbian, gay, bisexual, transgender, intersex, queer, asexual
MBS	Medicare Benefits Schedule
MDS	Minimum dataset
NACCHO	National Aboriginal Community Controlled Health Organisation
NCCI	National Cancer Control Indicators
NHDH	National Health Data Hub
NRWTD	National Radiotherapy Waiting Times Database
NSW	New South Wales
OCCAAARS	Ownership, control, custodianship, accessibility, accountability, amplifying First Nations, relevant, sustainability
OCPs	Optimal care pathways
OECD	The Organisation for Economic Co-operation and Development
ONDC	Office of the National Data Commissioner
PBCRs	Population-based cancer registries
PBS	Pharmaceutical Benefits Scheme
PLIDA	Person Level Integrated Data Asset
PREMS	Patient-reported experience measures
PROMS	Patient-reported outcome measures

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